Caregivers' attitudes towards HIV testing and disclosure of HIV status to at-risk children in rural Uganda

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Abstract

Caregivers of HIV-positive children were interviewed in the Mbarara and Isingiro districts of Uganda to identify current trends in practices related to HIV testing and the disclosure of HIV status to the child. A total of 28 caregivers of at least one HIV-positive child participated in semi-structured interviews exploring when and why they tested the child for HIV, when the child was informed of their positive status, and what the caregiver did to prepare themselves and the child for status disclosure. For nearly all (96%) respondents, the decision to test the child for HIV was due to existing illness in either the child or a relative. Major themes identified included caregivers stressing medication adherence when informing the child of their positive status and doubt that the children truly understood what was being explained to them when their status was disclosed. Most (65%) children were informed of their HIV status between the ages of 5 and 9, with the mean age of disclosure occurring at the age of 7 (±2) years. Caregivers reported that children began to learn about HIV at the same age they were informed of their positive status, and as many as two thirds (64%) of the caregivers sought advice from an HIV counsellor prior to disclosure. 45% of caregivers admitted to initially telling the child that they had a disease other than HIV, and this period of deceiving the child had a mean length of 3 (±2) years. 79% of caregivers reported that a child would be discriminated against in their community if the community learned of their HIV status, and 64% agreed that a child would feel that their life was without hope if they became aware of their HIV status. These findings suggest that while the age of HIV status disclosure in this setting is similar to what is recommended by current guidelines, the HIV disclosure experience in Mbarara and Isingiro districts differs with respect how caregivers prepare themselves and the child, and approaching disclosure as an ongoing process. The doubts expressed by caregivers regarding the child's level of HIV understanding following the disclosure experience suggest the children may be insufficiently prepared at the time of the initial disclosure event. The findings also suggest that examining the content of pre-disclosure counselling and HIV education, and how health care professionals are trained to facilitate the disclosure process as important avenues for further research.

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List of Abbreviations

3TC - Lamivudine

ABC - Abacavir

AIDS – Acquired Immunodeficiency Syndrome

ART – Antiretroviral Therapy

AZT – Zidovudine

EFZ - Efavirenz

FAOC – Foundation for AIDS-Orphaned Children

HIV – Human Immunodeficiency Virus

ISS – Immunosuppressive Syndrome

LPV/r – Lopinavir/Ritonavir

MUST – Mbarara University of Science and Technology

NNRTI – Non-nucleoside reverse transcriptase inhibitor

NVP - Nevirapine

TB – Tuberculosis

TDF – Tenofovir

WHO – World Health Organization

Chapter 1: Research Aims

Research Aims

The aim of this study was to interview primary caregivers of HIV positive children to identify trends related to the age of HIV testing and disclosure, how caregivers prepared themselves and the child prior to initiating disclosure, the methodology of disclosure, and caregivers' impressions of the effects and benefits of disclosing the diagnosis to the child.

Chapter 2: Literature Review

2.1 HIV in Uganda

Uganda is in the unique position to be an effective prototype for other Sub-Saharan African countries since it has one of the most mature HIV epidemics worldwide, and is one of the first countries to stabilize its HIV epidemic (Kahanen 2008). Currently, Uganda is home to an estimated 1.2 million people living with HIV (including 150,000 children), an estimated 1.2 million orphans due to HIV, and a national HIV prevalence among adults aged 15 to 49 of 7.2% (UNAIDS 2012). By contrast, the hardest-hit of the Sub-Saharan African nations can have HIV prevalence rates as high as 20%, with significantly higher rates of HIV incidence, mother to child transmission, and child mortality due to AIDS (UNAIDS 2010). For this reason, the challenges encountered by Uganda today may likely be encountered in the future by other nations as their own HIV epidemics stabilize. Likewise, research into HIV management and counselling strategies in Uganda may yield data that prove useful in future health policy development in other nations. The Mbarara and Isingiro districts in western Uganda are particularly attractive sites in which to conduct HIV research: their HIV prevalence has historically been greater than the nation overall and has an HIV prevalence most recently estimated at 8.0% (Government of Uganda 2014) and they possesses a variety of both remote rural and municipal settlements.

2.2 Children with HIV in sub-Saharan Africa

As the global HIV epidemic enters its fourth decade, significant advances have been made in HIV prevention and treatment in sub-Saharan Africa. While sub-Saharan Africa remains the hardest-hit region (accounting for the majority of HIV-related deaths, new HIV infections, and greatest HIV prevalence worldwide), the outlook for the area is beginning to show signs of improvement. Currently, sub-Saharan Africa is home to an estimated 24.7 million HIV-positive people, including 2.9 million children (UNAIDS 2014).

Improved HIV education and increased access to antenatal care have been credited with reducing the number of new infections reported annually, with an overall reduction of 45% in new HIV infections among children (UNAIDS 2014). This increasing access to antiretroviral drug therapies have reduced the number of HIV-related deaths (WHO 2013a). It is estimated that, in 2013, 34% of people in low and middle-income countries who required antiretroviral therapy (ART) were able to access it (UNAIDS 2013). Further, in 2013, 240,000 new HIV infections among children were recorded – a 58% drop in the HIV incidence rate among children from the rate in 2002 (UNAIDS 2014). As programs concerned with expanding the

accessibility of vital medication and education to low-income, high-burden areas continue apace, new challenges to HIV-related health promotion continue to present themselves.

One such challenge involves the increased proportion of HIV infected children who live through to adolescence due to increased access to life-saving drug therapies (Brady et al. 2010). As these children mature, the question of when and how they should be made aware of their diagnosis is raised.

2.3 Pediatric HIV Treatment Guidelines

Current WHO recommendations for HIV prevention, diagnosis and treatment stress the importance of early detection of the disease in at-risk children (WHO 2008). Initiating ART by 12 weeks of age in HIV positive children reduces HIV-related mortality by 75% (Violari et al. 2007). As stated above, it is estimated that 50% of all HIV positive infants who do not receive treatment with antiretroviral and antibiotic medications will die before reaching the age of two years old. For this reason, the WHO recommends HIV testing at 4 to 6 weeks of age for all children who are born to HIV positive mothers (WHO 2010a). If the child tests negative, a follow-up test at 18 months is also recommended to determine whether HIV was transmitted later, via breast milk (WHO 2010a, WHO 2006). Further, HIV testing and counselling is also recommended for all children presenting with below average growth or malnutrition in areas that are suffering from generalized epidemics (WHO 2010a). The overall goal of these guidelines is to permit initiation of treatment of the infected children before clinical signs of advanced infection present themselves.

Respiratory infections such as Pneumocystis pneumonia (PCP) is the most common cause of death among HIV positive infants (WHO 2006). For this reason, prophylactic use of co-trimoxazole is one of the most common drug therapies for HIV-positive children. A combination of sulfamethoxazole and trimethoprim, the antibiotic has activity against many pathogens that opportunistically infect the lungs of HIV positive individuals. The WHO currently recommends co-trimoxazole prophylaxis for all HIV-exposed infants from 4-6 weeks of age until they are confirmed to be HIV negative and are no longer being exposed to potential sources of infection such as breast milk from an infected mother (WHO 2006). In infants that are found to be HIV positive, co-trimoxazole is recommended until at least one year of age (WHO 2006). For children over 1 year old, the decision to initiate or continue co-trimoxazole is made based on CD4 cell count or the stage of infection (WHO 2006). Randomized controlled trials have established the efficacy of co-trimoxazole therapy in reducing morbidity and mortality of infants and children with HIV (Chintu et al. 2004).

Antiretroviral therapy is another key HIV treatment that has been shown to slow the progression of HIV infection, maintain CD4 cell levels, and improve the length and quality of life of those infected with HIV

(Fassinou et al. 2004, Mermin et al. 2008). Current WHO guidelines recommend ART to be initiated in all children infected with HIV below 5 years of age, regardless of WHO clinical stage or CD4 cell count (WHO 2013b). For children 5 years of age and older, all children with CD4 cell counts of 500 cells/mm^3 or less, regardless of clinical stage, are also recommended to receive ART (WHO 2013b). It is also recommended by the WHO that any children infected with HIV with severe or advanced symptomatic disease (WHO stages 3 or 4) receive ART regardless of CD4 count (WHO 2013b). Finally, it is recommended by the WHO that ART be initiated in any child younger than 18 months who has received a presumptive clinical diagnosis of HIV (WHO 2013b).

The above-cited guidelines recommend an ART regimen consisting of lopinavir and ritonavir (LPV/r) for all HIV positive children younger than 3 years of age. Nevirapine (NVP) – based regimens are the preferred alternative if LPV/r is not feasible (WHO 2013b). These general recommendations change to a abacavir (ABC), lamivudine (3TC) and zidovudine (AZT) regimen in the event that they have active tuberculosis (TB), reverting to the prior regimen once the duration of the TB treatment has elapsed (WHO 2013b). For children 3 years of age and older, efavirenz (EFV) is the preferred non-nucleoside reverse transcriptase inhibitor (NNRTI), while NVP is the preferred alternative. Adolescent ART recommendations align with adult regimens, typically consisting of either tenofovir (TDF), AZT or ABC in combination with 3TC (WHO 2013b).

In order to receive the benefits of ART, patients must maintain near perfect adherence to the therapy. Compliance rates below 90% have been associated with increased frequency of drug resistance and increased risk of opportunistic infections (Vreeman et al. 2008). The need for high adherence rates can be impeded by the challenging nature of the regimens themselves; requiring multiple medications to be taken multiple times per day increases the risk of missed or delayed doses (Brogley et al. 2005). Additionally, pediatric HIV infection is often associated with cognitive delays and depression, which are also predictive of reduced rates of adherence (Brown et al. 2000). In addition to these factors, the child's knowledge of their HIV infection, or lack thereof, is another factor with the potential to influence a child's adherence to ART (Williams et al. 2006, Paterson et al. 2000, Chi-Ling and Rosemary 1999).

2.4 HIV Testing of Children in sub-Saharan Africa

It is currently estimated that less than half (48%) of people with HIV know their status (UNAIDS 2014). The WHO recommends that, in areas with generalized epidemics, testing and counselling that is linked to prevention, treatment and counselling, be available not only in provider-initiated settings but also be available in the wider community (WHO 2013b). In spite of these recommendations, many barriers to HIV testing exist, especially where children are concerned. Often, the child has never been tested for HIV due

to a lack of access to testing services or reluctance on the part of caregivers to get the child tested; indeed, current research suggests that those who are most likely to benefit from HIV testing services and drug therapies, especially in rural or low-income areas, are typically not receiving them (WHO 2010b). A recent Ugandan study has suggested that, for the majority of caregivers of HIV-positive children, the decision to test the child for HIV occurs only after the child begins exhibiting symptoms of illness (Rwemisisi et al. 2008).

In other cases, the testing of children who are exposed to HIV is delayed due to a perceived lack of benefit versus risks involved – the typical progression of the disease in untreated children can lead to the belief that children who are infected are beyond help. Currently, the majority of HIV positive children are diagnosed only when they begin experiencing severe illness, and thus have a poorer prognosis than those diagnosed while asymptomatic (Rwemisisi et al. 2008, Kline 2006). Further, recent studies have shown that parents and caregivers are reluctant to have children tested out of fear of the emotional impact a positive diagnosis would have on the parents themselves, as well as uncertainty over what benefits would exist from knowing the child's HIV status (Vreeman et al. 2010). These attitudes were especially common for parents of younger children that were years from sexual maturity and thus considered to be at low risk of spreading the disease if they were, in fact, HIV positive. The study also suggested that these attitudes toward the testing of children were related, at least in part, to inconsistencies in recommendations for the testing of children. These inconsistencies in the recommendations have only been remedied and communicated to patients in sub-Saharan Africa in the past decade (Uganda Ministry of Health 2005).

The elimination of mother-to-child transmission of HIV by 2020 is a target of UNAIDS' 2016-2021 strategy (UNAIDS 2015a), and in Uganda a reduction in annual HIV incidence among children from 27,660 to 9,629 has been observed between 2011 and 2013 (Government of Uganda 2014). It has been estimated that 94% of expectant mothers attending antenatal clinics in Uganda received counselling and testing for HIV in 2011 (AVERT 2015). Recent efforts to scale-up the elimination of mother-to-child transmission resulted in 77% of positive mothers in 21 Global Plan Priority countries receiving ARV's (UNAIDS 2015b). It is estimated that 20% of new HIV infections in Uganda are due to mother-to-child transmission, although this may be significantly higher since many births in Uganda occur in rural areas outside of healthcare centres (AVERT 2015). Even if mother-to-child transmission of HIV had been eliminated entirely in Uganda by 2015, the Ugandan Ministry of Health projected that as many as 176,948 children under 15 with HIV would remain (Government of Uganda 2014) and would still require appropriate disclosure of their HIV status. Should the goal of zero mother-to-child transmission by 2020 become a reality, the issue of disclosure of HIV status to positive children will similarly remain a relevant one for the foreseeable future.

2.5 Disclosure of Diagnosis to HIV Positive Children

As an increasing proportion of HIV infected children live through school age and into adolescence due to increased access to life-saving drug therapies, the issue of HIV status disclosure becomes increasingly relevant (Brady et al. 2010). As these children mature, the question of when and how they should be made aware of their diagnosis is raised. For those that have been tested, many HIV-positive children are not informed of their status (Kouyoumdjian et al. 2005, Waugh 2003) and are ultimately unaware of their HIV status even if currently receiving treatment (Flanagan-Klygis et al. 2002).

A 2012 literature review of articles published between 1996 and 2012 found that the average rate of HIV status disclosure to positive children was 29.5% overall, with studies taking place in industrialized countries, predominantly the United States, having disclosure rates over twice that of low-to-middle income countries, predominantly in sub-Saharan Africa (Vaz et al. 2008, Pinzón-Iregui et al. 2012). The review identified many common threads in the 15 year span of literature, including a lack of support and guidance for caregivers with respect to the disclosure process and a need for evidence-based guidelines. Although one would expect the disclosure rates to trend upward in more recent studies, the rates reported in the more recent studies set in low-to-middle income countries still ranged from as low as 3% to a high of only 41% (Vreeman et al. 2010, Weiner et al. 1994, Oberdorfer et al. 2006, Menon et al. 2007, Bhattacharya et al. 2010). A more recent systematic review focused solely on resource-limited settings (Vreeman et al. 2012) showed similar disclosure rates while identifying that HIV status disclosure was typically viewed by caregivers as a one-time event as opposed to an ongoing process. A recent study in South Western Uganda suggests that only 31% of HIV positive children age 15-17 have been informed of their HIV status, while nearly half of the children are completely unaware of their condition (Atwiine et al. 2014). Common barriers to disclosure identified in this review included fear that the child would disclose his or her HIV status to others, stigma, fear of stigma, concern for the child's emotional or physical health, belief the child was not ready or too young, and a feeling of being unprepared for the disclosure process or event (Kiwanuka et al. 2014, Vaz et al. 2010).

To date, the majority of research into the disclosure of a diagnosis of long-term, potentially fatal disease has involved chronic diseases such as cancer as opposed to HIV (Katz and Jau 1984, Slavin et al. 1982, Beale et al. 2005), and many of the HIV disclosure guidelines that currently exist are derived from such work (New York State Department of Health AIDS Institute 2009). These guidelines recommend HIV counsellors and other health care professionals work with the caregiver to develop a 'disclosure plan' that takes into account the needs and goals of the caregiver, the child, and the rest of the family (New York State

Department of Health AIDS Institute 2009). The most recent guidelines published by the WHO recommend that children of school age have their positive status disclosed to them, with younger children being informed incrementally as they mature; however, the quality of evidence upon which these recommendations are based is noted to be 'low' (WHO 2011). More recently, a formal disclosure framework based on the child's stage cognitive development has been proposed in the United States (Cantrell et al. 2013).

These recommendations are based on research drawing on Piaget's theory of cognitive development (Bibacu and Walsh 1980). Specifically, research into children's understanding of concepts of illness and disease states that children in the Concrete Operational stage of development, as described by Piaget (Piaget 1952) are capable of understanding concept of illness and how an illness affects the body (Bibacu and Walsh 1980, Lipson 1993). Occurring approximately between the ages of 7 and 11, children in the Concrete Operational stage are characterized by an increase in logical thought, including the logical ability known as conservation (Piaget 1952). Conservation refers to the understanding that properties of an object remain, or are conserved, even when other properties change (Piaget 1952). A classic example to test for Conservation involves showing the child two identical glasses filled with equal volumes of water, getting the child to confirm that the volumes are equal, and then transferring the water from one glass into a pair of taller and thinner glasses. A child exhibits conservation if he or she is able to recognize that the new vessels contain the same amount of water as the original vessel (Piaget 1952).

Although researchers have identified the Concrete Operational stage as the optimal time to disclose a diagnosis to a child (Bibacu and Walsh 1980), it is possible that current guidelines overlook important characteristics of many HIV positive children. As mentioned above, the most recently published World Health Organization guidelines on HIV testing and disclosure recommend disclosure to all children aged 6-12 while younger children should be informed of their status "incrementally to accommodate their cognitive skills and emotional maturity" (WHO 2011). Currently, 91% of all HIV positive children live in Sub-Saharan Africa (UNAIDS 2014), a region that differs greatly from where Piaget conducted his research. Up to 50% of children initiated on ARV therapy in African HIV treatment programs are undernourished (Balton-Moore et al. 2007). Severe malnutrition, sufficient to cause stunted growth, is linked to structural and functional damage to the brain, which may delay cognitive development (Dewy and Begum 2011). Even in situations where malnutrition is not severe, early nutritional intake is a predictor of later cognitive ability (Freeman et al. 1980, Sigman et al. 1991). For these children, the standard recommendation of disclosure at 'school age' may result in disclosure too early for them to reasonably understand. This issue may be compounded if an attempt were made to disclose to even younger children, incrementally or not. Unless caregivers and health care professionals evaluate each child individually to

ensure that they are in the Concrete Operational stage prior to enacting their disclosure plan, it is even possible that current best practices would not produce the best outcomes for children in Sub-Saharan Africa.

Factors including the age of the child at the time of disclosure, method of disclosure, and involvement of health care professionals or counsellors could conceivably affect whether the disclosure process is beneficial and empowering or traumatic (Flanagan-Klygis et al. 2002, Vaz et al. 2010, Lipson 1993). The Uganda Ministry of Health's most recently published guidelines recommend that counsellors determine whether the caregiver is willing to discuss HIV and the test results before counselling is initiated, and that counsellors work with the caregivers of an HIV-positive child to plan for the child's future care (Uganda Ministry of Health 2003).

Although it seems logical that the manner by which an HIV-positive child learns his or her HIV status would have significant repercussions on the child's psychological state, medication compliance, and overall well-being, minimal research into this question has been conducted in the developing world. Research performed in Sub-Saharan Africa suggests that disclosure of HIV status is often viewed as a discrete event, as opposed to a process (Atwiine et al. 2014, Kiwanuka et al. 2014), but to date few studies in Uganda or elsewhere in sub-Saharan Africa have examined how caregivers choose to prepare themselves and the child prior to disclosure.

Interviews with health care professionals reveal a common belief that non-disclosure can lead to a change in adherence to daily medication regimens (Mellins et al. 2002), and increased depression and anxiety among children infected with HIV (Flanagan-Klygis et al. 2002, Bikaako-Kajora et al. 2006), but the evidence to date in sub-Saharan Africa remains statistically insignificant (Uganda Ministry of Health 2003) and highly subjective Vreeman et al. 2010, Bikaako-Kajora et al. 2006). Other research has examined the many potential barriers to disclosure for caregivers of HIV-positive children: focus groups of primary caregivers in South Africa identified stigma, lack of knowledge and communication skills related to HIV, and emotional unpreparedness as factors leading to an overall lack of comfort discussing HIV with the positive children under their care (Kouyoumdjian et al. 2005) The fear of stigma, in particular, is often cited as a major barrier to disclosure of a child's HIV status. As the majority of HIV-positive children were infected perinatally, biological parents of HIV-positive children have reported concern that their child would blame them (Kouyoumdjian et al. 2005, Oberdorfer et al. 2006). Similarly, many parents of HIV-positive children are reluctant to disclose the diagnosis to the child in order to protect them from the stress of keeping such a secret from the community and to spare them the emotional trauma of knowing that they are suffering from a terminal disease (Waugh 2003).

Research investigating the results of disclosing the HIV diagnosis to positive children has, to date, produced positive results. A 2007 study investigating Romanian children and teens identified an association between a lack of HIV status knowledge and disease progression up to and including death (Ferris et al. 2007). Other studies conducted in industrialized countries indicate that children who are aware of their positive status fare better in terms of medication compliance, coping mechanisms, and overall well-being than children who are unaware of their HIV status (Vaz et al. 2008, Weiner et al. 1994, Ferris et al. 2007, Blasini et al. 2004).

A recent study in Southwestern Uganda suggests that only 31% of children aged 5-17 have been informed of their HIV status, while nearly half of the children are completely unaware of their condition (51). HIV status knowledge has implications with respect to drug compliance, health behaviours, and the child's overall prognosis (Lipson 1993), but many hospitals in Uganda currently lack formal policies and procedures for disclosing a positive HIV diagnosis to a child (Rwemisisi et al. 2008, Mellins et al. 2002). Another study of 42 HIV positive children and their caregivers at the Mildmay HIV/AIDS centre in Kampala investigated whether a link existed between a child's adherence to their HIV medication and whether their HIV infection has been disclosed to them (Bikaako-Kajura et al. 2006). Over the course of semi-structured interviews lasting 1-3 hours, the researchers found that only 29% of the children had been informed of their HIV status, 38% were unaware of their specific diagnosis but were deemed as having 'partial disclosure' – the knowledge that they had an illness of some kind – and 33% were completely unaware of any illness. Children who were aware of their HIV status exhibited increased rates of self-reported adherence to drug therapy, whereas children who were never informed were more likely to report lapses in their adherence. Further, a lack of disclosure was often associated with intentional non-adherence to HIV-related drug regimens once the child finally learned the truth.

These results appear consistent with those from other studies conducted in Africa (Vaz et al. 2008, Balton-Moore et al. 2007), Thailand (Oberdorfer et al. 2006) and the developed world (Weiner et al. 1994, Blasini et al. 2004), There remains, however, a lack of evidence in sub-Saharan Africa to determine optimal timing and methodology of HIV disclosure. Just as importantly, there has been little research into how the disclosure process typically unfolds in Uganda and how effective it is in the eyes of stakeholders. Thus, the aim of this study was to interview primary caregivers of HIV-positive children using a qualitative methodology to identify trends related to the age disclosure occurs, how caregivers prepare themselves and the child for the disclosure process, exactly how this process occurs, and the challenges faced during the testing and disclosure process. This information can then be used to determine what 'best-practice' looks like in this demographic in terms of positive patient outcomes.

Chapter 3: Methods and Study Design

3.1 Ethics Approval

This study was approved by the University of Saskatchewan's Behavioural Research Ethics Board, the Mbarara University Institutional Research Ethics Committee (MUST-IREC) and the Uganda National Council for Science and Technology.

3.2 Selection and Recruitment of Caregivers

The study evaluated qualitative data collected from interviews with caregivers of HIV- positive children in the Mbarara and Isingiro districuts in Uganda, recruited from Mbarara University of Science and Technology (MUST) Immune Suppression Syndrome (ISS) clinic and at parish meetings for the Foundation for AIDS Orphaned Children (FAOC). All caregivers presenting for routine visits at the ISS clinic were screened against the inclusion criteria by nursing staff. Each eligible caregiver was approached in the waiting area and invited to participate in an interview to be conducted in a private room within the ISS clinic. In rural parishes of Isingiro district, FAOC beneficiaries were addressed by FAOC staff at monthly parish meetings; the study was announced verbally in English, Runyankole and Luganda (where appropriate) to attendees of the meetings. Attendees were provided with contact information for the study and were encouraged to contact the researchers to arrange a day and time to be interviewed. Such interviews were conducted at the interviewee's home or another suitably private site. All consenting participants were interviewed. Inclusion criteria were as follows:

(i) Primary caregiver of at least one HIV-positive child (age 0-14);

(ii) Caregiver acknowledges that child has been informed of his or her HIV status. The interviewer were not required to restrict their responses to only this child if they cared for multiple children; and

(iii) At least one child is receiving antiretroviral therapy or prophylactic antibiotic therapy.

The second criteria served two purposes: it ensured that participating caregivers had experienced the disclosure experience at least once, while enabling caregivers of multiple children to discuss the experiences

they had with children who may not know their status. Written informed consent was obtained in English, Runyankole, or Luganda as appropriate.

In situations where the participant's literacy level prevented written informed consent from being obtained, an equivalent verbal consent agreement was made available. The Ethics committees at both institutions as well as the Uganda National Council for Science and Technology approved these consent procedures. The reading of the form was recorded, and interviewees providing consent were asked to verbally assent to continuing the interview as well as indicating on the consent sheet using either a signature or thumbprint. Participants were informed that their involvement was entirely voluntary and that they may choose to not answer questions if uncomfortable, and may stop the interview at any time.

3.3 Use of Translators

A translator fluent in English, Runyankole, and Luganda and specifically trained to assist in administering the interview questionnaire was present for interviews where the volunteer was unable to conduct the interview in its entirely in English. Using mock interviews, translators were trained to ensure complete fidelity to what was actually said by the interviewer and interviewees without paraphrasing or embellishment, consistency between interviews, and signed a confidentiality agreement prior to assisting in the study. All interviews were transcribed by a second translator, who was instructed to look for any discrepancies between what was said by interviewees and what was reported by the primary translator (where applicable).

3.4 Interview Content

The interview questionnaire was designed with assumptions of naturalistic inquiry in mind, particularly Phenomenology – the belief that the object of interest should be examined without any preconceived notions or expectations – and Presupposition-less research – that the researcher does not assume that his or her norms, values or ideology are shared with the interview subjects. To this end, interviews consisted primarily of open-ended questions that encouraged the caregiver to build a narrative of their experiences informing the child of their HIV positive status. Questions focused on the caregiver's experiences and attitudes regarding the experiences of HIV status testing and the disclosure of the status to the child. Closed-ended questions that aimed to collect numeric and categorical data, such as age of disclosure, were also included. All closed-ended questions were followed up with open-ended questions where caregivers were encouraged to describe in their own words the reasoning and context of behind their responses. Interviews were semi-structured and took 45-75 minutes to complete.

3.5 Coding of Transcripts

Text files of all interview transcripts were imported into HyperResearch 3.5.2. Responses to open-ended questions were used, both individually and collectively, to generate word counts. Frequently used words were examined for context and used to generate the code book. These codes were then applied to transcripts in order to identify recurring themes in the responses.

Chapter 4: Results

4.1 Characteristics of Caregivers and Children

A total of 28 caregivers were interviewed (Table 4.1.1), of these 21 were the biological parent of the child and 19 of whom self-identified as being HIV positive. Disclosure experiences of 31 children were discussed during the course of the study.

Table 4.1.1: Characteristics of Caregivers and Children

Characteristic	Frequency	%[a]	Characteristic	Frequency	%[a]
Age of Caregiver (Years)			Occupation of Caregiver		
19	2	7	Owns business	4	14
21-30	5	18	Labourer	6	21
31-40	12	43	Farmer	10	34
41-50	7	25	Hawker	2	4
51-60	1	4	Mechanic	1	3
60+	1	4	Hairdresser	1	3
Caregivers			Tailor	1	3
Male	5	18	Works in shop	1	3
Female	23	82	Cook	1	3
Marital Status of Caregiver			None	2	7
Married	12	43	Place of Dwelling		
Divorced	7	25	Urban	2	7
Widowed	5	18	Small town	4	14
Never married	4	14	Village	22	79
HIV Status of Caregiver			People in Household		
Positive	21	75	2 – 4	7	25
Negative	5	18	5 – 7	17	61
Not tested	1	4	8 +	4	14
Declined to say	1	4	Child's Age (years)		
Relationship to Child			0 – 5	3	10
Biological parent	21	68	6 – 10	14	45
Step parent	5	16	11 – 14	14	45

Grandparent	1	3	Child's Age at Diagnosis (years)		
Aunt/Uncle	1	3	0 – 5	22	71
Great Aunt/Uncle	1	3	6 – 10	9	29
Brother	1	3	11 – 14	0	0
			Children Experiencing Partial Disclosure Before Full Disclosure	13	42
Teacher	1	3			

[a] Percentages may not total 100% due to rounding

4.2 Challenges Reported by Caregivers of HIV Positive Children

When participants were asked to describe in their own words the challenges they face as caregivers of HIV positive children, several themes were identified by the frequency of specific words that were used in the responses (Fig. 1). Caregivers most commonly mentioned difficulty in affording transportation, which was described as being a barrier to keeping appointments at the hospital. Difficulty in affording nutritious food for the child was another common challenge reported by caregivers. Finally, many caregivers reported difficulty in caring for the positive child when the child had fallen ill.

Challenges directly related to the child's HIV-related medications were also mentioned in the caregivers' responses, but much less frequently than those dealing with transport, food security and illness. Such challenges included with the child's medication adherence, lapses in medication availability, and concerns over the side effects of the child's medication.

4.3 Attitudes and Behaviours Related to HIV Testing

Although difficulty affording transportation was the most common challenge reported by the caregivers (Fig. 1), this did not appear to be a significant roadblock to HIV testing or counselling; a majority of all caregivers interviewed considered it relatively easy to access HIV testing and counselling services in their community. Of caregivers who were themselves tested for HIV, a majority chose to do so in response to existing illness either in themselves, their spouse, or the child under their care (Table 4.3.1). Similarly, the reasons cited by caregivers for getting the child tested for HIV were overwhelmingly related to the child, the parent, or another family member exhibiting signs of illness (Table 4.3.2) with vast majority of children being tested as a response to symptoms of illness in themselves or others. The age at which children were tested for HIV varied greatly (Table 4) and no children were reported to have been tested as part of standard postnatal care (Table 4.3.2). Among interviewed caregivers, most reported having the child tested for HIV early in the child's life, with a majority disclosing the child's status by the age of 7 (±2) years (Table 4.3.3).

Figure 4.3.1: Word Cloud of Responses to "Describe the challenges you face as the caregiver of an HIV-positive child."

Table 4.3.1: Reason for testing self for HIV.

Reason	Frequency[a]	%[b]
Encouraged by community leaders to get tested	1	3
Tested as part of antenatal care	3	10
Child was sick/weak	2	7
Spouse got sick or died	5	17
Felt sick/weak	10	34
Just wanted to know HIV status	5	17
Child tested positive for HIV	2	7
Wanted to know if sexual partner was HIV positive	1	3

[a] Frequency may not total n=28 due to responses in multiple categories

[b] Percentages may not total 100% due to rounding

Table 4.3.2: Reason for testing child for HIV.

Reason	Number of Caregivers	% of Caregivers

	Reporting this Reason[a]	Reporting This Reason[b]
Child was sick/weak	23	74
Parent was sick or died	6	19
Sibling was sick/weak	1	3
Parent was known to be positive	3	10
Recommended by health care worker	1	3
Caregiver wanted to know status of child's father	1	3
Tested as part of standard postnatal care	0	0

[a] May not total n=31 due to responses in multiple categories

[b] Percentages may not total 100% due to rounding

Table 4.3.3: Age in Years of Key Events in Disclosure Process.

Event	Mean (Years)	SD (Years)
HIV Testing	4	3
Initiation of HIV Education/Information Process	7	2
Partial Disclosure of HIV Status	6	2
Full Disclosure of HIV Status	7	2
Interval Between Testing and Disclosure	3	3
Interval Between Initiation of HIV Information and Disclosure	<1	<1
Interval Between Partial and Full Disclosure	3	2

Table 4.3.4: Person Most Responsible for Providing HIV Information

Relationship	Frequency	Percent
Caregiver Alone	25	84%
Counsellor Alone	1	3%
Caregiver and Counsellor Together	3	10%
Other Relative	1	3%

4.4 Attitudes and Behaviours Related to Informing Children about HIV

The data showed that the process to begin informing on HIV was initiated at a mean age of 7 years old (Table 4.3.3). When the HIV information process was described by the caregivers, the caregivers identified themselves as being most responsible for informing the child about HIV, either by themselves or in concert with an HIV counsellor, in nearly all cases (Table 4.3.4). When asked to describe the process by which the children were informed about HIV, the caregivers' responses revealed several themes. First, many caregivers expressed doubt that the child understood what they were being told, especially when the child learning about HIV was below the age of 7 (Text box 4.4.1).

Text Box 4.4.1: Selected responses illustrating emerging theme of doubts that the child truly understood when informed of their HIV status.

"The first time [we disclosed] I wasn't sure if she understood. Now I know she knows." (Biological mother, 38 years old, HIV positive, Status disclosed at age 5).

"She asks me every time, like every two months she will ask me why she has to swallow the medicines." (Biological mother, 29 years old, HIV positive, Status disclosed at age 7).

"He didn't react [when told]. I didn't notice a change, as if he didn't understand." (Biological father, 44 years old, HIV positive, Status disclosed at age 5).

"He didn't react [when told] … He is too young to know." (Biological mother, 50 years old, HIV positive, Status disclosed at age 7).

A lack of reaction on the part of the child was another sign caregivers interpreted to mean when explaining their feelings that the child did not understand (Text box 4.4.1). Other caregivers reported that the child felt, or might feel that their diagnosis was a death sentence, with 68% believing that a child would feel that their life was without hope if they knew their status (Text Box 4.4.2, Fig. 4.4.2).

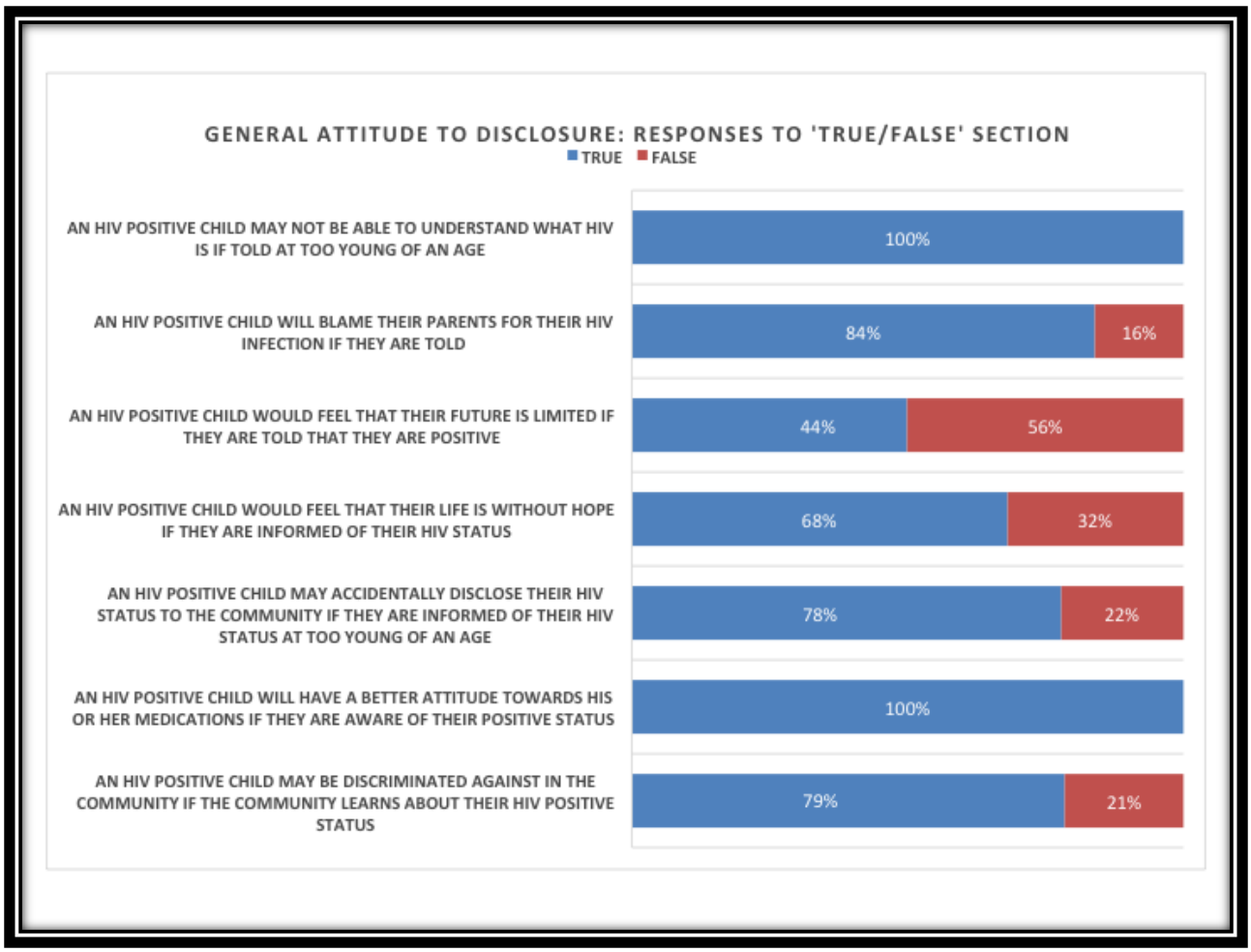

Figure 4.4.2: Caregiver Responses to Questions in True/False Section

Text Box 4.4.2. Selected responses given when asked to expand on True/False answer to statement: "An HIV-positive child will feel that their life is without hope if informed of their HIV status"

Caregivers who said "True" (68%):

"Because after her elder [10 year old] sister had learned that [her younger sister] was HIV positive, she told the grandmother that she should poison [her] so she could die, because there is no future." (Biological mother, 29 years old, HIV positive, Status disclosed at age 7).

"From the moment you tell the child they have AIDS, I think they will lose hope, because you will think you will die any time. Later on, they may understand that the ARVs [antiretroviral medications] will help them live longer." (Brother, 19 years old, HIV status unknown, Status disclosed at age 8).

"One child I knew refused to swallow his ARVs because he felt he didn't have a future." (Biological mother, 30 years old, HIV positive, Status disclosed at age 6).

"True, because they don't really know what AIDS is. They don't know that with ARVs they can still live longer." (Uncle, 56 years old, HIV negative, Status disclosed at age 7).

"True, because they think that at any time they are going to die." (Biological mother, 38 years old, HIV positive, Status disclosed at age 5).

Caregivers who said "False" (32%):

"Because if they informed him or talked to him more about HIV he won't feel that way." (Biological father, 45 years old, HIV negative, Status disclosed at age 6).

"If you tell the truth, and tell her that she will live longer with medication she won't lose hope." (Biological mother, 36 years old, HIV positive, Status disclosed at age 6).

"…if you tell them when they are young they will think that HIV is normal, since they are growing up like [other children]." (Biological mother, 36 years old, HIV positive, Status disclosed at age 6).

"If the child thinks that they can be cured, they won't lose hope." (Stepmother, 24 years old, HIV positive, Status disclosed at age 3).

4.5 Attitudes and Behaviours Related to Disclosure of HIV Status

Following initial open-ended questions, caregivers were read a brief section of statements and asked whether they felt the statements were mostly true or mostly false (Fig. 4.4.2). The purpose of this section was to act as a comparison to open-ended responses recorded earlier in the interview as well as to prompt additional open-ended questions.

Many attitudes and expectations related to HIV disclosure were shared by the caregivers interviewed. All caregivers felt that a child who knows his or her HIV status will have a "Good attitude towards his or her medications". However, a significant majority of caregivers relayed that a child with HIV would blame their parents for their HIV infection if their status were disclosed (Text Box 4.5.1), and many reported that children who are HIV positive are discriminated against in their community (Text Box 4.5.2, Fig. 4.4.2).

Text Box 4.5.1. Selected responses given when asked to expand on True/False answer to statement: "An HIV-positive child will blame their parents for their HIV infection if they are told."

Caregivers who said "True" (84%):

"…those who got the AIDS from their parents will blame them because they are the ones who infected them." (Biological parent, 30 years old, HIV positive, Status disclosed at age 5).

"Because they feel that they are innocent, and if the mother didn't have AIDS they would be free." (Biological mother, 40 years old, HIV positive, Status disclosed at age 7).

"I think the child would think that, if my mom didn't have AIDS, [the child] would be free." (Biological mother, 36 years old, HIV positive, Status disclosed at age 7).

"They would blame the parents because the child is innocent, and it's the parents who gave them the disease." (Uncle, 56 years old, HIV negative, Status disclosed at age 7).

Caregivers who said "False" (16%):

"False, because if they have taught him and shown him how HIV is spread, they won't blame it on the parents." (Biological father, 45 years old, HIV negative, Status disclosed at age 6).

Text Box 4.5.2. Selected responses given when asked to expand on True/False answer to statement: "An HIV-positive child will be discriminated against in your community if the community learns of the child's HIV status."

Caregivers who said "True" (79%):

"…the majority are not informed about AIDS. They tend to think that, if [the child] goes with them, he will spread the disease." (Biological father, 45 years old, HIV negative, Status disclosed at age 6).

"They may have misconceptions, like that AIDS is spread through sharing food. They may not want the children to play together." (Biological mother, 36 years old, HIV positive, Status disclosed at age 7).

"Our relatives and community members were telling her that she was already dead, that she has no use." (Biological mother, 38 years old, HIV positive, Status disclosed at age 5).

"True, because I see her cousins pinpoint her and refuse to eat with her." (Biological mother, 29 years old, HIV positive, Status disclosed at age 7).

"When they know you are positive, they tend to push you away, children especially." (Grandfather, 73 years old, HIV negative, Status disclosed at age 8).

"Yes. Some people tend to think that, when the child eats food with other children who are HIV negative, they think the HIV would spread. Or, when they play games, [the child] could hurt themselves and spread HIV." (Biological mother, 40 years old, HIV positive, Status disclosed at age 7).

"True, because they think that they will spread the HIV to others." (Biological mother, 38 years old, HIV positive, Status disclosed at age 11).

"They think the child will spread the sickness to their children." (Brother, 19 years old, HIV status unknown, Status disclosed at age 8).

"Because they will think they will spread the disease to the children who are negative." (Biological mother, 39 years old, HIV positive, Status disclosed at age 9).

Caregivers who said "False" (21%):

"False, because at the time many people are infected with HIV." (Biological mother, 30 years old, HIV positive, Status disclosed at age 5).

"…people know how HIV is [sic] and they will take it as normal." (Biological mother, 43 years old, HIV positive, Status disclosed at age 13).

Nearly half (42%) of caregivers admitted to initially telling the child that they were sick with a disease other than HIV (Table 4.1.1), with malaria being the most common disease mentioned in this way. This partial disclosure occurred at a mean age of 6 years (Table 4.3.3). When prompted to discuss their motivations for deceiving the child, a theme of feeling that the child was too young or otherwise unable to understand emerged (Text box 4.4.1). Among other caregivers who chose to partially disclose the illness to the child, many expressed fears about how the child will react to the knowledge.

Full disclosure of HIV status, when it occurs, typically happens at age 7 (Table 4.3.3). Similar to the pattern observed with respect to who is most responsible for providing the child information on HIV, the caregiver interviewed identified themselves as the person who disclosed the status to the child in the vast majority of cases (Table 4.5.1). The amount of time between when the child first began to be informed about HIV and the initial disclosure event was less than a year in the vast majority of cases (Table 4.3.3).

When asked to describe the process by which caregivers prepared themselves and the child prior to the initial disclosure event, two main yet contrasting themes were evident. Responses commonly described seeking out an HIV counsellor or health care professional for advice on what they should say or do when they disclosed the status. When pressed for additional details as to the type of instruction these information sources provided, caregivers were unable to provide specifics. The other theme common to many responses was a lack of preparation of any kind before initiating disclosure. In either case, the decision to disclose was made in response to the child asking questions about his or her medication or refusing to either take the medication or attend regular clinic appointments (Text Box 4.5.3).

Table 4.5.1 Person who disclosed HIV status to child.

Person	Frequency	%
Caregiver	23	82
Other relative	2	7
Doctor	2	7
HIV counsellor	1	4

Text Box 4.5.3. Selected responses to question: "What made you decide to tell the child that he or she had HIV?"

Caregivers who mentioned medication adherence as main or sole reason:

"Because she asked why she was taking her medicine." (Biological mother, 30 years old, HIV positive, Status disclosed at age 5).

"I wanted him to not refuse to take his medicine." (Biological mother, 36 years old, HIV positive, Status disclosed at age 6)

"I was asked why she was swallowing the medicine, and I told her the truth." (Biological mother, 36 years old, HIV positive, Status disclosed at age 7).

"[she] had been refusing medicines, and the hospital advised us to tell the child" (Grandfather, 73 years old, HIV negative, Status disclosed at age 8).

"We wanted him to know so he would take his medicines well and on time" (Biological father, 44 years old, HIV positive, Status disclosed at age 5).

"She was asking why she had to swallow the medicine." (Biological mother, 36 years old, HIV positive, Status disclosed at age 6).

"I saw that she was mature, and she was asking why she was taking the medicines." (Biological mother, 38 years old, HIV positive, Status disclosed at age 10).

When asked to describe what they said during the initial disclosure event, HIV positive caregivers commonly reported disclosing their own HIV status to the child at the same time they disclosed the child's. Similarly, caregivers who were not the biological parent of the child commonly reported informing the child that his or her parent was also HIV positive as part of the initial disclosure event. Caregivers also described stressing to the child that taking their HIV-related medications was crucial to their health and future, although many also reported telling the children that their antiretroviral medications would eventually cure them of the disease (Text Box 4.5.4).

Text Box 4.5.4. Selected responses to question: "Please tell me, in your own words, what you said [when you disclosed the status to the child]?"

"I told her that I was sick, and that when I gave birth to you, you were sick. But don't worry, we will both swallow the medicine and we will be fine. It will make us both good. In time, we won't need to swallow the medicine because we will be healed." (Biological mother, 39 years old, HIV positive, Status disclosed at age 9).

"He [the doctor] told him that he was tested and found HIV positive, but that I am going to give you this medicine to take and with time you'll be okay." (Stepmother, 24 years old, HIV positive, Status disclosed at age 5).

"I told him, if you don't swallow the medicine, you are going to become very sick like the way you were before. Also, I told him that he got AIDS when I was giving birth to him." (Biological mother, 36 years old, HIV positive, Status disclosed at age 6).

"I told him that the father spread the HIV to me and he was born with HIV. I also warned him that he needs to take his medicine regularly." (Biological mother, 30 years old, HIV positive, Status disclosed at age 6).

"I told her to fear AIDS and I told her how it is spread. Then I told her that she got it from us, the parents. Finally, that she should take the drugs and never spread it to others." (Biological mother, 38 years old, HIV positive, Status disclosed at age 10).

"I told him that you are HIV positive and you are to be on this medication for the rest of your life." Biological mother, 43 years old, HIV positive, Status disclosed at age 13).

"I explained to her that she and I were both sick, and that she should learn to love herself the way she is. Also left her under the care of her godmother if I wasn't there anymore." (Biological mother, 36 years old, HIV positive, Status disclosed at age 7).

"When she was leaving for boarding school, I sat her down and told her to take her medicine. I also told her to not share any sharp instruments with your friends because you could spread HIV. She asked me, 'I have HIV?' and I said 'Yes, you got it when I was producing you". (Biological mother, 38 years old, HIV positive, Status disclosed at age 5).

"I told her that your father recently passed away. He died of AIDS. Also, you are born with AIDS. You need to take your medicine, it will help you to live longer." (Biological mother, 29 years old, HIV positive, Status disclosed at age 7).

"[when leaving hospital] I asked him 'Do you know where we are coming from, and what we were doing there?' He said no. I told him, 'You are there to collect this medicine. This medicine is for HIV, and you are HIV positive. And the HIV, you got it from your parents." (Uncle, 56 years old, HIV negative, Status disclosed at age 7).

"We told him that he had HIV, that he got it from both his parents from birth when his mother was producing him. We told him about what his medicines do, how the ARVs help him." (Biological father, 44 years old, HIV positive, Status disclosed at age 5).

4.6 Perceived Effects of HIV Status Disclosure

Of those caregivers who described the experience of disclosing HIV status to an HIV-positive child under their care, 80% believed that the way in which they did so was a "good idea" and that disclosing the status to the child resulted in positive outcomes (Text Box 4.6.1). However, an important theme emerged following disclosure was the doubt expressed by the caregiver whether the child understood what they were being told. This theme recurred in the accounts of multiple caregivers and across the full range of ages of disclosure (Text Box 4.4.1).

Text Box 4.6.1. Selected responses to the question: "Do you think that telling the child when you did and how you did was the right decision?"

Caregivers who said "Yes" (80%):

> "At that age, the child was ready and could understand what it meant [to have HIV]." (Biological mother, Age 30, HIV positive, Status disclosed at age 5)
>
> "I wanted her to know in case I die that she has AIDS, and so she wouldn't learn it from other people." (Biological mother, Age 40, HIV positive, Status disclosed at age 7)
>
> "If I didn't tell him, he would still be refusing to swallow his medicine." (Stepmother, Age 24, HIV positive, Status disclosed at age 3).
>
> "Yes, he is determined to swallow his medicine." (Stepmother, Age 24, HIV positive, Status disclosed at age 5).
>
> "I wanted him to know, so he wouldn't be asking so many questions about why he was swallowing the medicine." (Biological mother, Age 36, HIV positive, Status disclosed at age 6).
>
> "I wanted her to be comfortable with her life, not compare herself to everyone who doesn't have it, and also not to blame me because she got AIDS through me." (Biological mother, Age 36, HIV positive, Status disclosed at age 7).

Caregivers who said "No" (20%):

> "She wanted to hang herself. She went down to this river nearby to drown herself. We stopped her on the way there… I took her to the hospital to close her in a room for a week so she wouldn't hurt herself." (Stepmother, Age 38, HIV positive, Status disclosed at age 9).
>
> "The child started hating herself after I told her she had AIDS. Also, at that age I don't think she was ready to hear it." (Biological mother, Age 29, HIV positive, Status disclosed at age 5).
>
> "No, because the child wasn't old enough at the time … I should have told him at around 7 years." (Biological father, Age 45, HIV negative, Status disclosed at age 5).

4.7 Triangulation of Results Within Methodology

Caregiver responses tended to remain consistent throughout individual interviews. However, three notable exceptions are described below.

When asked to tell the interviewer a story about a time when the child under their care missed a dose of ARVs or antibiotics, 39% said the child never missed a single dose. Within this subgroup, however,

responses to open-ended questions revealed an emergent theme of difficulties in medication compliance Medication compliance was reported to either be improved following HIV status disclosure, or as a result of the child being informed of their HIV status because they were refusing to take their medication. This inconsistency may suggest that a proportion of caregivers may be reluctant to openly admit instances of medication noncompliance, a phenomenon that has been previously observed in multiple studies (10, 30). Alternatively, the apparent discrepancy between results could reflect that children were reluctant to take medications pre-disclosure, and that this reluctance was diminished following disclosure.

Another discrepancy occurred between caregiver response to the statements “An HIV-positive child will feel that their life is without hope if informed of their HIV status” and “An HIV positive child will feel that their future is limited if informed of their HIV status.” (Fig. 4.2) While 68% responded true to the first statement and 44% responded true to the second statement, only 68% of these caregivers responded to both statements in the same way. Upon further discussion, it became clear that the caregivers were interpreting the term “future” to refer to the child’s prospects of obtaining an education or employment.

Finally, caregivers’ general attitudes toward disclosure were surprisingly negative, with caregivers agreeing that children who learn their positive status may be discriminated against in their community, feel their life is without hope, or blame their biological parents for their infection (Fig. 4.2). These attitudes were present among caregivers despite 80% of them believing that disclosing HIV diagnosis to children under their care was the right decision (Text box 4.6.1). This may be due to the caregivers observing the negative outcomes experienced by other members of their community during their own disclosure experiences, a rationale that was mentioned by several caregivers.

Chapter 5: Discussion

5.1 Disclosure Experience of Interviewees vs. Current Guidelines

When looking at the disclosure experiences of caregivers from start to finish, several key differences from current guidelines become apparent. Current recommendations for disclosing a child's HIV status include the formation of a disclosure plan between the caregiver and an HIV counsellor that takes into account the family's dynamics, the child's intellectual development, and the goals of the caregiver. Once the plan is in place, the child should be informed about the disease in a developmentally appropriate manner prior to the initial disclosure event. Once informed of their HIV status, guidelines suggest that the child and caregiver continue to discuss the child's HIV status and its impact on their life in growing complexity as the child matures intellectually (New York State Department of Health AIDS Institute 2009, WHO 2011). However, the caregivers' responses indicated that more than a third (36%) of the respondents embarked on disclosing the status to the child without first seeking help. Many more caregivers expressed doubts that the child had indeed understood what they were being told. This is supported by recent research involving caregivers of HIV-positive children in Mbarara, Uganda as well as in the Democratic Republic of Congo, both of which suggest that caregivers tend to view HIV status disclosure as a single step as opposed to an ongoing process (Kiwanuka et al. 2014, Vaz et al. 2010). This lack of involvement on the part of health care workers and HIV counsellors in the pre-disclosure preparation may lead to sub-optimal or harmful disclosure experiences.

The narratives provided by the caregivers looked at who they sought out for advice regarding disclosing the HIV status to the child and what they did to prepare themselves and the child before the initial event. None of these narratives touched upon whether these choices were made against the advice of their health care providers. Further, when caregivers were able to describe the nature of advice provided to them by HIV counsellors or other health care workers, none of these descriptions included expected points such as approaching disclosure in a stepwise manner, the formation of a disclosure plan, or the counsellor acting as a facilitator for the HIV information and disclosure process.

5.2 Who Discloses Status

In nearly all cases, it was the caregiver or another relative who disclosed the HIV diagnosis to the child. Only rarely, in 11% of cases (Table 4.3.4), was the HIV status initially disclosed by a health care worker such as a physician or HIV counsellor. This is in line with data from multiple other studies conducted throughout Sub-Saharan Africa (Atwiine et al. 2014, Vaz et al. 2010). Current recommendations do not specify who should disclose the diagnosis to an HIV-positive child, be it caregiver, counsellor or health

care professional, so long as that person is selected while being mindful of the effect of HIV status disclosure on the child's well-being (Cantrell et al. 2013, WHO 2011).

5.3 Education of Child Regarding HIV

The data collected here suggest that, regardless of the age of disclosure, provision of HIV information tends to begin immediately prior. Thus, children with little or no HIV knowledge may be inundated with information in a relatively short period of time, culminating in the disclosure of their HIV status. This occurred over a wide range of intervals (Mean = 3 years, SD = 3 years) between the child testing positive and the initial disclosure event (Table 4.3.3). Learning their HIV status in this manner, as opposed to a more stepwise approach that tailors the information given to the child's intellectual development, may lessen the positive effects of disclosure.

5.4 Partial Disclosure

The rate of partial disclosure reported by interviewees revealed that nearly half of all positive children were first only told that they were sick, or were told that they had a disease other than HIV. Further, among children who experienced partial disclosure prior to full disclosure, this deception would typically last for several years. This practice reflects the caregivers' reported doubts that the children were capable of understanding full disclosure of their HIV status, but the duration of partial disclosure may also suggest a reluctance to fully disclose that was not explicitly addressed in the interview responses. In either case, the frequency and duration of partial disclosure represent an aspect of the disclosure experience that may be a target for future interventions.

5.5 Results of Disclosure

Across the entire range of disclosure ages, there was a persistent theme of caregivers doubting that the children fully understood the information shared at the time of disclosure. This may be due to baseline differences in the quality or extent of instruction the child and caregiver received prior to beginning the disclosure process, something that was not controlled for in this study. Another possible explanation is that the malnutrition common in HIV positive children may result in delays in cognitive development. To date, the existence of a link between malnutrition and poor HIV disclosure outcomes has not been investigated and thus provides the opportunity for future study. If a link were found it could mean that, for this patient population, the optimal ages to begin the HIV education process and disclosure process may differ from those recommended by current guidelines

Many caregivers responded in the affirmative to the statement that a child would feel that their life is without hope if they learned of their status (Fig. 4.2). The reported reactions of some of the children who learned their status, which ranged from confusion to stoic acceptance to self-harm or attempted suicide, lends credence to this. As access to counselling does not appear to be a significant roadblock, educating caregivers and counsellors in the steps to take prior to disclosure (e.g., planning how to disclose with a counsellor and ensuring that the child has a baseline knowledge of HIV including the knowledge that the disease should not be considered an automatic death sentence) may be pertinent steps to change the disclosure experiences of Ugandan families that may result in more positive outcomes for at-risk children. A longer-term study, where positive children are followed through the disclosure process and beyond, would be the logical next step to identify potential benefits of a more formalized disclosure process that stresses education of caregiver and child. Identifying the baseline instruction health care providers in the area receive regarding HIV disclosure to pediatric patients would be a key first step to completing such a study. Further, assessing the children's HIV knowledge directly throughout the education and disclosure process would provide more robust data on the child's true disclosure experience.

5.6 Caregivers' Attitudes Regarding HIV Status Disclosure

Caregivers' attitudes towards HIV status disclosure were frequently negative, with the overwhelming majority believing that the child would feel that their life was without hope when they learned their status, that they will blame their parents for their HIV infection if told, and/or that they would accidentally disclose his or her status to the community (Fig. 4.2). Interestingly, even caregivers who reported a positive disclosure experience shared the beliefs that disclosure would have negative consequences. Despite these admissions, all (100%) of caregivers believed that disclosure would result in the child having a better attitude toward their medications.

In spite of efforts to promote HIV testing as part of routine medical care, the vast majority of HIV tests discussed in the interviews were motivated by active symptoms – either in a child, parent, sibling, spouse, or the individual themselves. The fact that nearly every respondent viewed HIV testing and counselling services as easy to obtain in their community suggests that more education and outreach may be necessary to convince at-risk individuals in rural Uganda to get tested for HIV before they fall ill. Such efforts would also serve to address the fact that the vast majority of interviewees report that, in their communities, HIV-positive children would be discriminated against if their status becomes known (Fig. 4.2).

5.7 Limitations

The study suffers from several limitations. Although the sample size of 28 caregivers discussing the experiences of 31 children is more modest than some contemporary studies examining HIV status disclosure in Sub-Saharan Africa, this is largely due to the decision to restrict participation in the study to caregivers who had fully disclosed the HIV diagnosis to the child under their care. As recent evidence in the area suggests (Atwiine et al. 2014), this decision would exclude 69% of caregivers presenting at the ISS clinic. Further, the sample size used is significantly larger than many relevant qualitative studies recently released (Chi-Ling and Rosemary 1999, Vaz et al. 2010).

Similarly, as the study design selected for caregivers who lived in a specific region of Uganda, attended a specific ISS clinic, had disclosed the HIV status to at least one child under their care, and who was caring for at least one child who was receiving ARV therapy or antibiotic prophylaxis, the experiences of these caregivers may not be representative of the majority of caregivers of HIV positive children in Southwestern Uganda, let alone Sub-Saharan Africa. Although the experiences of caregivers in this study were similar to those reported in other studies (Atwiine 2014, Kiwanuka et al. 2014), it would still be premature to declare these experiences to be the norm.

As little was known about the disclosure experiences of the caregivers of HIV-positive children when this study was being designed, questions were approached using the assumptions found in Naturalistic Inquiry in order to avoid inadvertently projecting the researcher's preconceptions and biases on the results. Although this decision allowed interviewees to build their own narratives about their experiences with HIV testing and disclosure, the approach meant that the data collected could not be subjected to the same statistical analysis that the data obtained from a more closed-ended survey. Future studies can draw upon the results of this study to generate a more focused questionnaire without fear that issues important to the caregivers are being marginalized.

Another potential limitation involves the challenge inherent in conducting semi-structured interviews via interpreters. Although all translators employed in the study were extensively trained and urged to strive for consistency between all interviews, using mock interviews to identify and address potential issues before they were encountered, some caregivers clearly interpreted certain questions differently than others. To avoid steering interviewee responses to the researchers' preconceptions or putting words in the subjects' mouths, the interviewees were simply requested to clarify their position before responses were coded 'as is'. By using a second translator to validate the first translation, we feel that all questions and answers are recorded as accurately as possible using this method.

The original study design was going to compare the responses of caregivers recruited at the ISS clinic with those recruited through FAOC. As we began to collect data, however, we noticed that there was significant overlap between the two groups. For one thing, caregivers recruited via FAOC were often receiving their treatment in Mbarara and caregivers recruited at the ISS clinic often were living in the rural parishes surrounding Mbarara. Thus, the rural vs. municipal comparison was not possible, as the two methods of sampling were drawing participants from the same populations.

The recruitment process was designed so that neither the interviewers, health care workers, nor FAOC chairpersons would be able to influence who would be invited to participate. Hence that decision to pool the data from the two sampling methods would not introduce bias. In the ISS clinic, all caregivers presenting were screened and, if found to be eligible, all were invited to participate. At FAOC meetings, all members were informed of the study at meetings and were encouraged to contact us if they felt that they met the criteria and were interested in participating. The only potential difference in the two groups would be that the caregivers approached directly at the ISS clinic would be more likely to participate than those who were simply made aware of the study at FAOC meetings and had to take the additional step of contacting us to volunteer. We noticed greater numbers of participants volunteering through the ISS clinic vs. the FAOC meetings and thus directly comparing the two groups may not necessarily be valid. The level of education of the caregiver and their detailed knowledge about HIV AIDS was not specifically addressed and may have been different between the ISS clinic and the FAOC groups, but the mixing of the groups would mitigate any effect. The ethical challenges inherent in interviewing HIV positive children with potentially different levels of awareness of their HIV status prevented the researchers from directly assessing each child's level of HIV knowledge. It would be unacceptable, for example, for an interviewer to accidentally disclose the child's HIV status to him or her if the caregiver was somehow misinformed as to the child's knowledge of their own HIV status. For these reasons, the study was less concerned with the exact knowledge possessed by the children as opposed to understanding when the process of informing began for each child with respect to HIV, and how this fit into the disclosure process. The downside to this focus is that the study is dependent on caregivers being able to accurately assess the extent to which a child understood when they were informed of their HIV status. For this reason, it is possible that the number of children who do not fully understand the realities of their HIV infection following disclosure differs from what caregivers reported. Directly assessing the HIV knowledge of the children involved and how that knowledge changes throughout a stepwise disclosure process will be a crucial component of future research into this topic.

Interview format is, historically, an unreliable way to accurately assess medication adherence, as it introduces both recall and social desirability bias, often resulting in patients over-reporting adherence

(Miller and Hays 2000, Wagner and Rabkin 2000). For this reason, the study does not investigate potential relationships between a child's disclosure experience and their drug compliance. Ultimately, determining any effect of disclosure method on drug compliance will be important, especially once the child in question reaches an age where they take responsibility for administering their own medications. In such a scenario, review of medication refill timings and trends in CD4 counts will likely produce the most accurate picture of overall medication compliance.

Finally, many of the questions depend on the recall of the caregiver. As such, the narrative built by each interview to describe the disclosure process and results is subject to the limitations of the caregiver's memory. To combat this, the questionnaire was designed to avoid influencing what aspects of HIV testing, education, and disclosure the caregiver chose to focus on, instead encouraging the caregivers to speak about issues and experiences that were important to them.

Chapter 6: Conclusion

Overall, disclosure experiences reported by caregivers may be resulting in sub-optimal outcomes. HIV testing of children was almost always initiated due to symptoms of illness in either the child or a relative. Informing the child that they had a disease other than HIV was common, and this partial disclosure tended to last several years before full disclosure was attempted. Over one third of all caregivers reported not preparing at all before attempting to disclose the status to the child, and only two caregivers described ensuring that the child had an understanding of what it meant to have HIV before attempting disclosure. As a potential result of these characteristics of the disclosure experience, many caregivers described informing the children of their diagnosis before the child was able to fully understand the disclosure, and this disclosure appeared to be a discrete event, as opposed to an ongoing process, in nearly all cases. As access to HIV counselling was not deemed to be a roadblock by all but a few caregivers, changing disclosure practices may be as simple as providing more concrete guidelines for HIV counsellors to follow to ensure that positive children are adequately informed about HIV prior to disclosure once there is evidence of the child having entered the Concrete Operational phase. Whether such changes will result in measurably better outcomes is a question that merits further study.

Chapter 7: Future Directions

An inability to consistently assess the nutritional status of children from birth through to the date of the interview meant that the question of whether malnutrition affects the optimal age of disclosure remains unaddressed in this paper. Although not presented in the results section of this paper as direct observation of the children was not part of the study design, interviewers did observe visibly stunted children on occasion before or after conducting the interview with the caregiver. A more thorough investigation of this characteristic of HIV positive children in this setting seems absolutely warranted.

Knowing that HIV status disclosure to children in Uganda tends to occur at school age, be treated as a single discrete event as opposed to an ongoing process, and occur without advice from a health care provider or HIV counsellor, the opportunity exists to augment the disclosure process children experience and identify how these interventions alter the outcomes of disclosure. Standardizing the training of local HIV counsellors would be a logical next step. Specifically, staff would be encouraged to discuss the concept of disclosure with caregivers while the child is still in early childhood, promote the education of the child regarding concepts of illness prior to school age, and working with the caregiver to identify their concerns and priorities in order to develop a disclosure plan tailored for each child. This plan would encompass HIV education for both caregiver and child, helping the caregiver identify and overcome potential barriers to disclosure, and includes follow-up discussions with both the caregiver and HIV counsellors at subsequent clinic visits. The success of this manner of disclosure could be measured in many different ways. As a more thorough disclosure process would be hypothesized to result in improved coping skills and socialization for the child, caregivers could be interviewed in a manner similar to what was used in this paper. Effects on ARV medication adherence could be assessed as the child matures and assumes greater responsibility for his or her health, with the expectation that a more successful disclosure experience would result in increased rates of adherence. Ultimately, how a child learned of his or her positive diagnosis could also impact their CD4 counts as the child matures into adolescence.

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Appendix A: Interview Questionnaire and Informed Consent Forms

Research Topic: Assessment of caretakers' attitudes towards HIV testing and disclosure of HIV status to at- risk children in rural Uganda

Participant Number:

Place of Interview: (Tick)

Mbarara ISS Clinic
Household

Date of Interview:

DD **MM** **YYYY**

Initials of the caretaker:

Sex of the caretaker: (Tick)

Male
Female

Informed Consent Form (Luganda)

Interviewee's Name: _____

Interviewee Literate (YES/NO)

(If NO, form will be dictated by interpreter)

Abaana b'esomero elya University eya Saskatchewan mu Canada mukitongole eky'eddagala n'eby'endya (Department of Pharmacy & Nutrition).

Ntwala omukisa guno okwebaza okumpa omukisa okweyongela okumanya endowooza kumukenenya.

Ekigendererwa ky'omusomo guno kya kutuwa endowooza z'abantu kukukebeza n'okubeera n'akawuka kamukenenya mubaana; "musomo gwakunonyereza".

Essila mumusomo guno tulitadde kukukulakulanya okumanya ebizibu n'endowooza z'amaka, kubikwata kukubera omulamu n'akawuka ka mukenenya mubaana n'abantu abakulu.

Ekigendererwa kyaffe kwekumanya ebizibu mumaka, ekinatuyamba okutumbuula n'okwongera obuyambi n'okutekawo enkyuka kyuka. Tugenda kuyita mubufunze mumusomo n'okuwanyisiganya ebilowoozo ebiinaba bivuddemumusomo guno. Tugenda kuwuliriza ebikwata ku bantu bangi. Kiyinza obutakuyamba gwe ng'omuntu obwomu, wabula gw'omusomo gutukwatako fenna awaamu bwegunaba gumaze okugwa.

Okwetaba mumusomo gunno kwakyeyagalire era nga kwa bwelele, ngela togusasulira; naye tegugenda kukutawanya mumirimu gyo oba pulani yoona gyolina.

Bwoba t'oyagadde oyinza okutula n'otoddamu kibuuzo kyona bw'ekiba nga tekikuyisizza bulungi; naye era oyina orukusa orufuluma kusaawa yoona gyoba oyagadde.

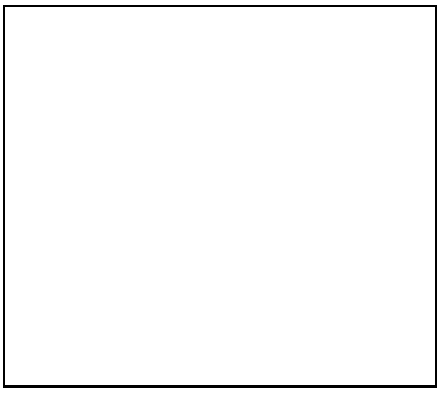
Omusomo gunno guyinza okumala eddakika nga 30 oba esaawa namba, okusinzira kunsonga zetunayogerako.

Okutekako omukono gwo kubbaluwa eno, kitegeza nti otegedde omusomo kyegutegeza era oyina n'omukisa ogubuza ebibuzo byonna byoyagala, era okiriiza okwetaba mumusomo.

Amaanya _____ nzikiliza omusomu.

Enaku z'omwezi _____

Thumbprint (If interviewee cannot provide signature)



Rick Lorenz, Omushomi Omukyondozi
College of Pharmacy & Nutrition
University of Saskatchewan
Saskatoon, SK. S7N 5C9
Tel: 0001 705 888 6123
Email: rfl978@mail.usask.ca

Adil J. Nazarali, Omulebelezi
College of Pharmacy & Nutrition
University of Saskatchewan
Saskatoon, SK. S7N 5C9
Tel: 0001 306 966 6334
Email: aj.nazarali@usask.ca

Informed Consent Form (Runyankole)

Interviewee's Name: _____

Interviewee Literate (YES/NO)

(If NO, form will be dictated by interpreter)

Nkabacondozi abaana b'eishomero lya University ya Saskatchewan omukitongolo (Department of Pharmacy & Nutrition), nitutwara omugisha ogu okwebeebaza okutuha omugisha gw'okweyongera kumanya emiturire n'emiteekatekyere y'abantu b'omubyanga bya Uganda bitari-bimwe-nabimwe aha bikwatiraine n'akakooko kasirimu.

Ebigyeendererwa by'omushomo ogu n'okumanya amakuru ahamitekateekyere y'Abanyauganda abari kutuura omubyalo, ahakakooko kasirimu, hamwe n'okukyebeza n'okutuura n'akokooko aka omubaana. Omushomo ogu gugyendereirwe ahabw'okucondoza. Itwe nk'abeegi nituteekateeka ngu omukukoresa omuringo ogu ogw'okucondoza nikiza kwongyera ahakumanya kwitu ahakakooko aka: ebizibu ebiri omukukyebeza akakoko kasirimu omubaana n'abantu abakuru, hamwe n'ebiri omumaka, nikwo tubaase kutunguura kandi n'okubaasa kutaho empinduka omumitwarize egyo.

Nituza kuraba omubugufu kumanya ebitekateko by'abantu mwena, nabwanyima nituza kuhikanisa n'okushugaanisa ebirarugyemu, obwo nitubihandiika aha mpapura.

Omushomo ogu nigureeba ahaby'abantu baingi barikugamba. Eki nikimanyisa ngu nigubaasa obutakuyamba iwe nk'omuntu, beitu kandi omukushuganisa ebiteekateeeko byabaingi, nikiija kubaasa kureetaaho okuhweerwa omushomo gwaheza kuhwa.

Okwija kwawe omumushomo ogu n'okweyendera t'okwokukusiisira emirimu yawe nari omwanya gwawe gwabusha.

Waaba n'oreeba ngu okubaho kwawe nokwokukusisiira n'obasa kureerera okubaho nari okutagarukamu ebibuzo ebirikuza kukubuuzibwa. Kandi nabwo, kuwakuteganisibwa omumushomo n'obaasa kushohora eshaha yonna obu orikwenda.

Omushomo nigubaasa kukutwarira edakiika nka makumi ashatu nari obundi guhitsye eshaha yoona.

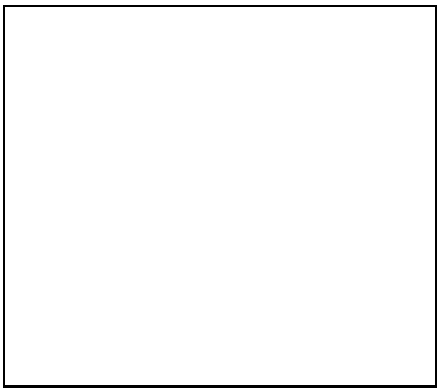
Okuta omukono gwawe aha baruha egi nikimanyisa ngu n'omanya w'amanya ebigyendererwa by'omushomo ogu.

Amaziina _____ naikiriza kwetaba omumushomo.

Ebiro by'okwezi _____

Omukono gwawe _____.

Thumbprint (If interviewee cannot provide signature)



Rick Lorenz, Omushomi Omukyondozi
College of Pharmacy & Nutrition
University of Saskatchewan
Saskatoon, SK S7N 5C9
Tel: 0001 705 888 6123
Email: rfl978@mail.usask.ca

Adil Nazarali, Omulebelezi
College of Pharmacy & Nutrition
University of Saskatchewan
Saskatoon, SK. S7N 5C9
Tel: 0001 306 966 6334
Email: aj.nazarali@usask.ca

Data Collection Questionnaire

A. BIOGRAPHICAL DATA

1. Place of residence……
2. Class of residence……..Town Dwelling / Country Dwelling
3. State age of the respondent in years……..
4. Marital Status of respondent: Single, Married, Divorced/Separated, Cohabiting, Widowed, Other (Specify _____)
5. Would you say it is easy to get HIV testing where you live? Yes/No (Code 1 = Yes; Code 2 = No)
    a. Please explain your answer:
    _____
    _____
    _____
    _____
    _____
    b. How far is it to your nearest location that offers HIV testing?
    _____
    c. How far is it to your nearest location that offers HIV counseling services?
    _____
6. Have you been tested for your HIV status? Yes/ No (Code 1= Yes; Code 2 = No)
    IF YES:
        i. When were you tested? _____
        ii. What made you decide to test?
        _____
        _____
        _____
        _____
        _____

_____

_____

iii. What is your HIV status? _____

IF NO:

i. What made you decide not to test?

_____

_____

_____

_____

_____

_____

_____

ii. What would make you decide to test?

_____

_____

_____

_____

_____

B. HOUSEHOLD DATA

1. State the number of people in each age range who are part of your household (including yourself)

   a. 0 – 4 years _____

   b. 5 - 9 years _____

   c. 10 – 14 years _____

d. 15 – 19 years _____

e. 20 – 24 years _____

f. 25 – 39 years _____

g. 40 – 59 years _____

h. 60 – 79 years _____

i. 80 years and older _____

2. Are all of the children (age 14 and under) in your household under your care?

_____

3. Who in your household earns the money?

_____

_____

_____

_____

4. How do the providers earn their money?

_____

_____

_____

_____

5. How much money, per month, would you say the household earns? _____

6. Does your household buy most of its food, or do you grow it yourselves?

_____

7. Tell me the challenges you deal with as the caregiver of an HIV positive child?

COMPLETE FOLLOWING SECTION FOR EACH CHILD UNDER INTERVIEWEE'S CARE:

INTERVIEWEE NUMBER (FROM FIRST PAGE) _____

AGE OF CHILD _____

ARE YOU THE BIOLOGICAL PARENT OF THIS CHILD? Yes/No (Code 1 = Yes; Code 2 = No)

IF NO:

What is your relationship to this child? _____

A. HIV TESTING HISTORY

1. Do you know the HIV status of this child? Yes/ No (Code 1 = Yes, Code 2 = No)

IF YES:

a) How old was the child when he or she was tested?

_____

b) What made you decide to get the child tested?

_____

_____

_____

_____

_____

_____

IF NO:

a) What made you decide to not get the child tested?

_____

_____

_____

_____

_____

_____

b) What would make you decide to get the child tested?

_____

_____

_____

_____

_____

_____

B. <u>DRUG THERAPY AND COMPLIANCE DATA (Complete only if child is HIV positive)</u>

1. Please tell us all of the medications the child is currently taking (Recorded by interviewer in the space below)
2. Please tell us all of the herbal or traditional medicines the child is currently taking (Recorded by interviewer in the space below)
3. If you can, please tell us what each medication is supposed to do for your child (Recorded by interviewer in the space below)
4. How often does the child take them? (Recorded by interviewer in the space below)
    i. Do they help? Yes/No.
    ii. Explain your answer

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

_____

5. What Challenges have you had involving the child's medication?

_____

_____

_____

_____

_____

_____

6. Do you feel that you need to trick or threaten the child into taking antiretroviral drugs or Septrin? Yes/No (Code 1 = Yes; Code 2 = No)

   IF YES:

   a) How do you trick them?

      _____

      _____

_____

_____

7. Do you ever reward the child under your care for taking their antiretroviral drugs or Septrin when they are supposed to? Yes/No (Code 1 = Yes; Code 2 = No)

   IF YES:

   a) How do you reward them?

_____

_____

_____

_____

8. What do you tell the child their HIV-related medication does?

_____

_____

_____

_____

_____

9. Has the child ever asked you any questions about their HIV-related medication? Yes/No (Code 1 = Yes; Code 2 = No)

   IF YES:

   a) What did they ask?

_____

_____

_____

_____

_____

   b) How did you respond?

_____

_____

_____

_____

_____

10. Has the child ever shown a desire to stop taking their HIV-related medication? Yes/ No (Code 1 = Yes; Code 2 = No)

    IF YES:

    a) How old were they when this happened?

    _____

    _____

    b) What did they say?

    _____

    _____

    _____

    _____

    _____

11. Was there a time when the child missed a dose of their antiretroviral drugs or their Septrin? Yes/No (Code 1 = Yes; Code 2 = No)

    IF YES:

    a. Tell me what happened.

    _____

    _____

    _____

    _____

    _____

    _____

12. What would need to change for the child to miss fewer doses of HIV-related medication?

_____

_____

_____

_____

_____

_____

C. <u>CHILD'S HIV LEARNING EXPERIENCE (Complete only if child is HIV positive)</u>

A. Do you ever talk to the child about HIV? (YES/NO Code 1 = YES, Code 2 = NO)
If YES:

a. What made you decide to talk to the child about HIV?

_____

_____

_____

_____

_____

b. How old was the child the first time you talked about HIV?

_____

c. Listen to the following questions about the child's HIV knowledge and tell us if your child knows the statement or not. If the child knows, say who told them (For example, you told them yourself, a family member told them, they learned at school, from a doctor, or some other source). Also tell us the age your child learned each statement.

d.

i. Does the child know that he or she has an illness?

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

ii. Does the child know that he or she will have this sickness for the rest of their life

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

iii. Does the child know that HIV exists?

a. Told [YES/NO] – Circle

b. Age: _____

c. By whom? _____

iv. Does the child know that he or she is HIV positive?

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

v. People with HIV may have a harder time fighting off sicknesses

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

vi. A person with HIV can develop AIDS

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

vii. A person with AIDS has an extremely hard time fighting off other sicknesses

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

viii. Certain HIV medications can help someone who is HIV positive be stronger and healthier

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

ix. Certain HIV medications can delay a person with HIV from developing severe illness (AIDS)

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

x. Certain HIV medications must be taken for the rest of a person's life

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

xi. Missing doses of certain HIV medications can make them less effective

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

xii. HIV can be spread through contact with blood

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

xiii. HIV can be spread through sex

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

xiii. HIV can be spread from a positive mother to her child through birth

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

xiv. A HIV positive woman who is nursing may spread HIV to the infant

a. Told? [Yes/No] – Circle

b. Age: _____

c. By whom? _____

If NO:

a. What made you decide to not talk to the child about HIV?

_____

_____

_____

_____

b. What would make you decide to talk to the child about HIV?

_____

_____

_____

_____

_____

_____

D. DISCLOSURE BEHAVIOURS (Complete only if child is HIV positive)

1. Please pick the following statement that best describes what you told the child about their HIV infection (Circle appropriate choice):
   i. They were told that they have HIV (FULL DISCLOSURE)
   ii. They were told that they were sick but were not told what illness they had (PARTIAL DISCLOSURE)
   iii. They have been told nothing at all (NO DISCLOSURE)

   (CODE 1 = FULL DISCLOSURE, CODE 2 = PARTIAL DISCLOSURE, CODE 3 = NO DISCLOSURE)

IF FULL DISCLOSURE:

a. How old was the child when they were told? _____

b. Were you the person who told them that they had HIV? Yes/No (Code 1 = Yes; Code 2 = No)
   i. IF YES:
      a. What made you decide to tell them that they had HIV?

_____

_____

_____

_____

_____

      b. Did anybody help you to plan what to say to the child? Yes/No (Code 1 = Yes; Code 2 = No)
         IF YES:
         1. Who helped you? (Circle all who apply: Family,

            Friends, School, HIV Counselor, Doctor, Nurse,

Support Group, Religious Leader, Other

_____)

IF NO:

a. Who told them? _____

b. Why was this person the one who told them?

_____

_____

_____

_____

c. Who else was present when the child was told that they had HIV?

_____

_____

____

d. How did you prepare yourself and the child for telling them that they had HIV?

_____

_____

_____

_____

e. Please tell us in your own words what was said to him or her

_____

_____

_____

_____

_____

_____

_____

f. Describe how did the child reacted when you told them

_____

_____

_____

_____

g. After telling the child that they have HIV, how often do you talk with the child about HIV?

_____

_____

_____

_____

_____

_____

h. Does the child know how they got HIV? (Yes/No: Code 1 = YES, Code 2 = NO)

IF YES:

i. How did they find out?

_____

_____

_____

_____

_____

ii. What were they told?

_____

_____

_____

_____

_____

iii. How old were they at the time?

_____

iv. How did they react when they learned how they got HIV?

_____

_____

_____

_____

_____

i. Do you think telling the child that they were positive when and how you did was the right decision? Yes/No (Code 1 = Yes; Code 2 = No)
   i. Explain your answer:

_____

_____

_____

_____

_____

j. Did you at first only tell them that they were sick? Yes/No (Code 1 = Yes; Code 2 = No)
   IF YES: Complete "IF PARTIAL DISCLOSURE" section as well

IF PARTIAL DISCLOSURE:

a. How old was the child when they were told?_____
b. Were you the person who told them that they had HIV? Yes/No (Code 1 = Yes; Code 2 = No)
   1. IF YES:
      a. What made you decide to not tell them everything?

_____

_____

_____

_____

_____

b. Did anybody help you plan what you were going to tell the child? If so, who?:

_____

_____

c. Please tell us in your own words what you said to him or her:

_____

_____

_____

_____

_____

_____

d. Did anybody help you decide what to say to the child? Yes/No (Code 1 = Yes, Code 2 = No)

IF YES:

1. Who helped you? (Circle all that apply: Family, Friends, Teachers, HIV Counselor, Doctor, Nurse, Support group, Religious Leader, Other (specify _____)

IF NO:

1. Who told them?

_____

2. Why were they the person who told them?

_____

_____

_____

_____

_____

e. Describe how the child reacted when they were told that they were sick:

_____

_____

_____

_____

_____

_____

IF NO DISCLOSURE:

a. What made you decide not to tell him or her?

_____

_____

_____

_____

b. Did anybody help you plan when you should tell the child? If so, who?

_____

_____

_____

c. When do you think would be the best age to tell him or her?

d. _____

i. Why do you believe that this is the best age?

_____

_____

_____

_____

_____

1. Have you disclosed the positive status of a child under your care to anyone else? Yes/No (Code 1 = Yes; Code 2 = No)

a. If YES

1. Who did you disclose to? (Relatives? Teachers? Priest? Other)?

_____

_____

_____

_____

2. What made you decide to tell these people?

_____

_____

_____

_____

_____

_____

E. ATTITUTES TOWARDS DISCLOSURE

1. I am now going to read several general statements about HIV. Tell me whether you think they are mostly true or mostly untrue. If possible, tell me what made you answer the way you did:

    a. An HIV positive child may be discriminated against in the community if the community learned of their HIV positive status

    _____

    _____

    b. An HIV positive child will have a good attitude toward their medication if they are aware of their positive status

    _____

    _____

    c. An HIV positive child will accidentally disclose their positive status to the rest of the community if the child is informed of their HIV status at too young of an age

    _____

    _____

    d. An HIV positive child would feel that their life is without hope if they are informed of their HIV status

    _____

    _____

    e. An HIV positive child would feel that their future is limited if they are told

    _____

    _____

    f. An HIV positive child will blame their parents for their HIV infection if they are told

    _____

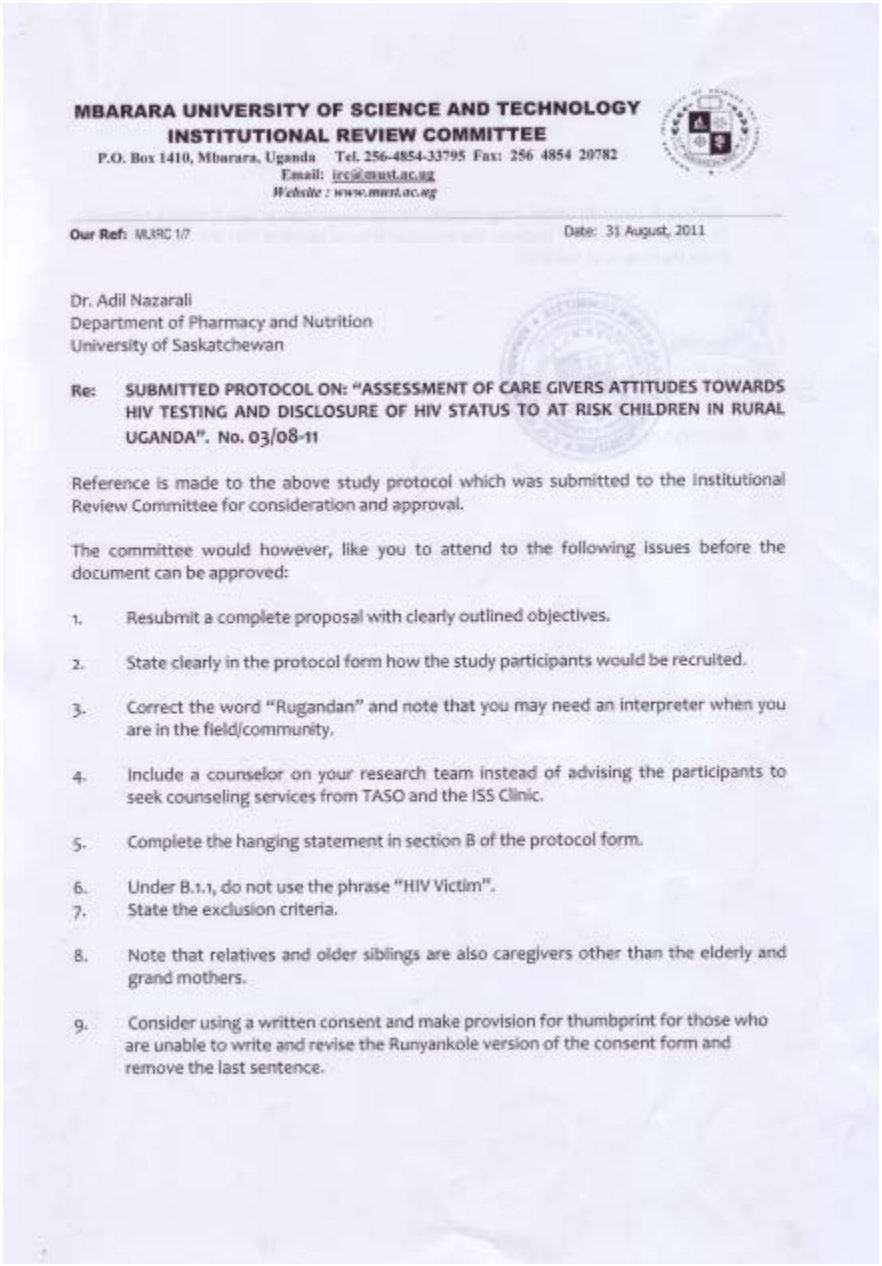
    _____

g. An HIV positive child may not be able to understand what HIV is if told at too young of an age

c. _____

_____

Appendix B: Changes to Research Proposal, Interview Questionnaire and Informed Consent Forms Proposed by MUST Ethics Committee



MBARARA UNIVERSITY OF SCIENCE AND TECHNOLOGY
INSTITUTIONAL REVIEW COMMITTEE
P.O. Box 1410, Mbarara, Uganda Tel. 256-4854-33795 Fax: 256 4854 20782
Email: irc@must.ac.ug
Website : www.must.ac.ug

Our Ref: MUIRC 1/7 Date: 31 August, 2011

Dr. Adil Nazarali
Department of Pharmacy and Nutrition
University of Saskatchewan

Re: SUBMITTED PROTOCOL ON: "ASSESSMENT OF CARE GIVERS ATTITUDES TOWARDS HIV TESTING AND DISCLOSURE OF HIV STATUS TO AT RISK CHILDREN IN RURAL UGANDA". No. 03/08-11

Reference is made to the above study protocol which was submitted to the Institutional Review Committee for consideration and approval.

The committee would however, like you to attend to the following issues before the document can be approved:

1. Resubmit a complete proposal with clearly outlined objectives.
2. State clearly in the protocol form how the study participants would be recruited.
3. Correct the word "Rugandan" and note that you may need an interpreter when you are in the field/community.
4. Include a counselor on your research team instead of advising the participants to seek counseling services from TASO and the ISS Clinic.
5. Complete the hanging statement in section B of the protocol form.
6. Under B.1.1, do not use the phrase "HIV Victim".
7. State the exclusion criteria.
8. Note that relatives and older siblings are also caregivers other than the elderly and grand mothers.
9. Consider using a written consent and make provision for thumbprint for those who are unable to write and revise the Runyankole version of the consent form and remove the last sentence.

10. Section B, page 19, under drug therapy, revisit the sentence 'skip if child is negative or status is unknown" because the inclusion criteria requires that the care giver must know the status of the child.

CHAIRMAN- MUST IRC

Cc Secretary –IRC

Appendix C: Guide for Interview Translators

Guide for Interview Translators

Introduction

Congratulations on your decision to act as a translator for this research study. As a translator, you are a vital link between the researcher and the interviewees, allowing them to communicate in a clear manner in spite of language barriers that would otherwise make discussion impossible.

Because of your vital role in the research process, the quality of your work will have a direct impact on the quality of the research provided; Even an extremely well-designed study will produce useless or misleading results if the translators are not properly instructed.

With this in mind, below please find a brief guide on the most important aspects of acting as a translator.

General Responsibilities

As a translator, you will accompany a researcher who is would ordinarily be conducting one-on-one interviews with volunteers. The researcher will not be adequately proficient in Runyankole or Luganda to conduct the interviews in these languages, and the interviewees will often not be sufficiently proficient in English to conduct the interview in that language. You will translate the questions and answers of the interview in order to facilitate the process.

During the interview, the researcher will direct questions directly at the interviewee. Once a question has been asked, you will repeat the question exactly as it was asked in the interviewee's language of choice. When the interviewee answers, you will translate their response exactly as it was answered into English. In the event that a response is excessively long, it is acceptable (in fact, encouraged) that you get the interviewee to pause while you translate what has initially been said to the researcher. Once the first part has been translated, prompt the interviewee to continue.

If you do not understand what an interviewee is saying, you may ask them to repeat themselves. It is important, however, that you include your question when translating the full exchange to the researcher.

Interviews will usually be recorded via audio tape or digital audio. In the event that an interviewee withholds consent to be recorded in such a manner, the researcher will need to record responses on paper. Obviously, the translation of such interviews will be much slower, and it may be necessary for you to prompt the interviewee to pause more frequently during long responses than you would if the interview is being recorded.

Confidentiality

As a translator, you will be in a position to learn extremely private information about the interviewee's health status and personal life. It is essential that all information you obtain in the course of the interviews remain between you, the researcher, and the interviewee. Any sharing of information obtained during the interview with anybody else, either verbally or in writing, will result in the translator's immediate

termination from the study. Legal action may also be taken where applicable against anybody responsible for confidential information being illegally shared.

Before you assist in your first interview, you will be required to sign a confidentiality agreement. This agreement states that you are aware of the confidentiality requirements and agree to not share any information you obtain in the study with anybody outside of the study, for any reason.

Similarly, you may find that an interviewee is somebody who you personally know. If this situation arises, you must inform the researcher before the interview begins. Depending on the nature of the relationship between you and the interviewee, an alternate translator may be selected. This will be at the discretion of the researcher who is to conduct the interview.

Precision

The ultimate goal of this research is to examine the experiences of a number of people in order to see what patterns, if any, exist. In order for research to be considered valid, each interview must be similar. That is, each interviewee must be asked the same questions in the same manner, and their responses must be recorded in a consistent manner. Simply put, you must be sure to translate the interview questions in an identical manner for every interview that you do.

When translating interviewee's responses to English, it is important that you translate what was said as precisely as possible. Below are some examples of errors that reduce the precision of a translator's work, and ways that they can be avoided:

a. Additions

   Additions happen when a translator reports something that the interviewee never actually said. Often, additions occur when the translator tries to clarify something said by the interviewee, in order to make things clearer for the researcher. Although done with the best of intentions, these additions will add the translator's own biases into the responses and make the data less valid. Concentrate on translating exactly what was said – if the interviewer wishes something to be clarified, they will ask a follow-up question to the interviewee, through you.

b. Omissions

   Omissions happen when something said by the interviewee is not translated. Not everything said by an interviewee will be relevant for the purpose of the study. Even so, it is important to translate everything said as precisely as possible and let the researcher decide what is relevant or not. An example of this would be if an interviewee is asked a "yes or no" question, but responds by telling a long anecdote. The translator, in an effort to keep the responses brief, tells the researcher only the 'yes or no' part of the response, ignoring the bulk of what was said. Although you may be tempted to shorten the response to just the requested yes or no, doing so harms the validity of the study.

   If you find that an interviewee's response is significantly long, it is best to ask the interviewee to pause while you translate what you have heard so far to the researcher. Once the researcher

has recorded what you have initially translated, prompt the interviewee to continue. By handling long responses in this manner, the odds of something being accidentally omitted are reduced.

c. Substitutions

Similar to additions, substitutions occur when a translator changes what is said by the interviewee in an effort to make things clearer for the researcher. Although done with good intentions, it is important for translators to translate exactly what was said, rather than putting the responses into their own words.

Substitutions can also occur when a translator is translating a long response from an interviewee, when items said at the start of the response become difficult to recall precisely. As mentioned above, it is best to pause an interviewee during an overly-long response, translate what was said so far, and then prompt the interviewee to continue.

d. Condensations

Similar to omissions, condensations occur when a translator shortens what is said by an interviewee in an effort to make things more concise or brief for the researcher. Much like the other actions described above, condensing an interviewee's response ultimately harms the study's results and the practice should be avoided.

e. Role Exchanges

Role exchanges occur when a translator replaces one person's role in a response with that of another person. For example, if the interviewee said that she was the caregiver of her sister's HIV positive child and the translator mistakenly said that the caregiver was the child's mother, this would introduce incorrect information into the study's results.

Mock Interview

Prior to performing your first interview in the field, you and another translator will have the chance to practice your skills in at least one mock interview. The goal of the mock interview is to ensure that each translator is capable and confident in their role before data collection begins.

During the mock interview, one translator will act as the interviewee, and use a written outline to answer interview questions in runyakole or luganda. The other translator will assist the researcher by translating during the interview. After one interview, the translators will switch roles, with the other translator pretending to be the interviewee, answering the questions in either runyankole or luganda according to a different outline.

Once both mock interviews are completed, the two translators and the researcher will discuss the responses and evaluate how accurately each interview was translated, and determine if any improvements can be made.

Confidentiality Agreement

I, the undersigned, hereby acknowledge that the interaction between interviewees, researchers, and myself is confidential in nature. Further, I agree to respect and maintain the confidentiality of all information exchanged during the interview. I acknowledge that any sharing of such information to any party outside of those present at the actual interview (myself, the researcher, and the interviewee), for any reason and by any method of communication, is a violation of that confidentiality. I am aware that, should I violate the confidentiality of the information, either intentionally or accidentally, I will be immediately terminated in my role of translator. Further, I may be subject to legal action pursuant to such a breach of confidentiality.

Name (Print) _____

Signature _____

Date_____